

Deliberative Democracy

Center for Advances in Public Engagement. (2008). *Public Engagement: A primer from public agenda*. New York: Public Agenda

Fishkin, J. S. (2006). Beyond polling alone: The quest for an informed public. *Critical Review*, 18(1-3), 157-165. doi:10.1080/08913810608443654

Fishkin, J. S., & Luskin, R. C. (2005). Experimenting with a democratic ideal: Deliberative polling and public opinion. *Acta Politica*, 40(3), 284-298. doi:10.1057/palgrave.ap.5500121

Gornick, M. C., Scherer, A. M., Sutton, E. J., Ryan, K. A., Exe, N. L., Li, M., . . . Vries, R. G. (2016). Effect of public deliberation on attitudes toward return of secondary results in genomic sequencing. *Journal of Genetic Counseling*, 26(1), 122-132. doi:10.1007/s10897-016-9987-0

Kim, S. Y., Wall, I. F., Stanczyk, A., & Vries, R. D. (2009). Assessing the public's views in research ethics controversies: Deliberative democracy and bioethics as natural allies. *Journal of Empirical Research on Human Research Ethics*, 4(4), 3-16. doi:10.1525/jer.2009.4.4.3

Odoherty, K. C., Hawkins, A. K., & Burgess, M. M. (2012). Involving citizens in the ethics of biobank research: Informing institutional policy through structured public deliberation. *Social Science & Medicine*, 75(9), 1604-1611. doi:10.1016/j.socscimed.2012.06.026

Newborn Screening

Goldenberg, A. J., Comeau, A. M., Grosse, S. D., Tanksley, S., Prosser, L. A., Ojodu, J., . . . Green, N. S. (2016). Evaluating harms in the assessment of net benefit: A framework for newborn screening condition review. *Maternal and Child Health Journal*, 20(3), 693-700. doi:10.1007/s10995-015-1869-9

Kemper, A. R., Green, N. S., Calonge, N., Lam, W. K., Comeau, A. M., Goldenberg, A. J., . . . Jr, J. A. (2013). Decision-making process for conditions nominated to the Recommended Uniform Screening Panel: statement of the US Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. *Genetics in Medicine*, 16(2), 183-187. doi:10.1038/gim.2013.98

Nicholls, S. G., Wilson, B. J., Etchegary, H., Brehaut, J. C., Potter, B. K., Hayeems, R., . . . Carroll, J. C. (2014). Benefits and burdens of newborn screening: public understanding and decision-making. *Personalized Medicine*, 11(6), 593-607. doi:10.2217/pme.14.46

Ethics related to Genetics and Newborn Screening

Bowen, M., Kolor, K., Dotson, W., Ned, R., & Khoury, M. (2012). Public health action in genomics is now needed beyond newborn screening. *Public Health Genomics*, 15(6), 327-334. doi:10.1159/000341889

Goldenberg, A. J., & Sharp, R. R. (2012). The ethical hazards and programmatic challenges of genomic newborn screening. *Jama*, 307(5), 461. doi:10.1001/jama.2012.68

Kwon, J. M., & Steiner, R. D. (2011). "I'm fine; I'm just waiting for my disease": The new and growing class of presymptomatic patients. *Neurology*, 77(6), 522-523. doi:10.1212/wnl.0b013e318228c15f

Lea, D., Kaphingst, K., Bowen, D., Lipkus, I., & Hadley, D. (2011). Communicating genetic and genomic information: Health literacy and numeracy considerations. *Public Health Genomics*, 14(4-5), 279-289. doi:10.1159/000294191

Lemke, A., Wolf, W., Hebert-Beirne, J., & Smith, M. (2010). Public and biobank participant attitudes toward genetic research participation and data sharing. *Public Health Genomics*, 13(6), 368-377. doi:10.1159/000276767

Hasegawa, L., Fergus, K., Ojeda, N., & Au, S. (2011). Parental attitudes toward ethical and social issues surrounding the expansion of newborn screening using new technologies. *Public Health Genomics*, 14(4-5), 298-306.
doi:10.1159/000314644

Morrison, M. (2016). Overdiagnosis, medicalisation and social justice: commentary on Carteret al(2016) 'A definition and ethical evaluation of overdiagnosis'. *Journal of Medical Ethics*, 42(11), 720-721. doi:10.1136/medethics-2016-103717

Tarini, B. A., Christakis, D. A., & Welch, H. G. (2006). State newborn screening in the Tandem Mass Spectrometry era: More tests, more false-positive results. *Pediatrics*, 118(2), 448-456. doi:10.1542/peds.2005-2026

Tarini, B., Clark, S. J., Pilli, S., Dombkowski, K. J., Korzeniewski, S. J., Gebremariam, A., . . . Gigoescu, V. (2011). False-positive newborn screening result and future health care use in a state Medicaid cohort. *Pediatrics*, 128(4).
doi:10.1542/peds.2010-2448d

Timmermans, S., & Buchbinder, M. (2010). Patients-in-waiting. *Journal of Health and Social Behavior*, 51(4), 408-423.
doi:10.1177/0022146510386794

Ziniel, S., Savage, S. K., Huntington, N., Amatruda, J., Green, R. C., Weitzman, E. R., . . . Holm, I. A. (2014). Parents' preferences for return of results in pediatric genomic research. *Public Health Genomics*, 17(2), 105-114. doi:
10.1159/000358539

New Conditions

Kemper, A. R., Brosco, J., Comeau, A., Green, N. S., Grosse, S., Kwon, J., . . . Lam, K. (2015). *Newborn Screening for X-Linked Adrenoleukodystrophy (X-ALD): A Systematic Review of the Evidence* (pp. 1-73, Rep. No. V.5). Rockville, MD: Maternal and Child Health Bureau.

<https://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/nominatecondition/reviews/alddecisionletter.pdf>

Kemper, A. R., Comeau, A. M., Green, N. S., Prosser, L. A., Ojodu, J., Tanksley, S., . . . Lam, K. (2015). *Newborn Screening for Mucopolysaccharidosis Type 1 (MPS 1): A Systematic Review of Evidence* (pp. 1-62, Rep. No. 1.1). Rockville, MD: Maternal and Child Health Bureau.

<https://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/nominatecondition/reviews/mps1finalreport.pdf>

Kemper, A., Comeau, A., Prosser, L. A., Green, N. S., Tanksley, S., Goldenberg, A., . . . Lam, K. (2013). *Evidence Report: Newborn Screening for Pompe Disease* (pp. 1-80, Rep.). Rockville, MD: Maternal and Child Health Bureau.

<https://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/nominatecondition/reviews/pompereport2013.pdf>